The expanding role of the paediatric endocrinology specialist nurse

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Disclosures

- Merck
- Ipsen
- Ferring
Introduction

- History of nursing in the UK
- Nursing stereotype
- Advanced nursing roles
- Nursing in paediatric endocrinology
History of nursing in the UK

- First school of nursing established in 1860
- 1940s
  - State Enrolled Nurse (SEN)
    - 2 years training
  - State Registered Nurse (SRN)
    - Registered General Nurse (RGN)
  - Launch of National Health Service (NHS)
- 1960s
  - First degree in Nursing
History of nursing in the UK

• 1990s
  – Diploma 3 year training
  – Post graduate education introduced

• 2000s
  – All graduate profession
  – Training university based
  – MSc level education
    • Doctorate / Phd
Nursing stereotypes
Nursing Stereotypes

• Doctors Handmaidens
  – Do nurses actually work *for* doctors
    • Training and education
    • Recruitment
    • Management structure
  – Co-workers
  – Daily care of patients
    • Liaison between patients and doctors
  – Autonomous profession
Autonomy ➔ Advanced practice

- Clinical Nurse Specialists
- Advanced Nurse Practitioners
  - Advancing roles
  - Expanding skills
Clinical Nurse Specialist roles

- Consultant
- Educator
- Liaison
- Researcher
- Collaborator
- Leader
- Change Agent
- Patient advocate
Guidelines for practice

- Focus on knowledge, skills and interventions specific to endocrine nurses
- References local and national guidelines
- Adheres to Benner’s (1982) ‘Novice to Expert’ concept
  - Competent practitioner
  - Experienced practitioner
  - Expert practitioner
Education for advanced practice

- Post-graduate pathways
- BSc
- MSc
  - Children’s Advanced Nurse Practitioner
Children’s Advanced Nurse Practitioner

- 3 year MSc course
- Accredited by the RCN
- Specialising in specific fields
Course Content

- Advanced clinical assessment
- Principles of physiology
- Non-Medical prescribing
- Managing the complex presenting child
- Leadership
- Research
- Dissertation
Furthering education in paediatric endocrinology

- Auxology course – St Bartholomew’s and The Royal London Hospitals
  - Growth measurement
  - Bone age reading
  - Growth clinic
- BSc Module – Keele University
- BSc / MSc module – London South Bank University
Principles of care of the child and young person in endocrinology

- Practice based assessment
  - Competency based booklet
- Formative assessment
  - Group work
- Summative assessment
  - Case study presentation
  - BSPED approved
  - January 2017
Module content

- The endocrine system
- The multidisciplinary team
- Growth and the IGF-1 system
- Puberty
- Adrenal disorders
- Disorders of Sex Development
- Thyroid disorders
- Disorders of salt and water balance
- Pancreas disorders
- Bone metabolism and bone health
- Late effects of childhood cancers
- Hormone replacement treatment
- Advanced nursing roles in paediatric endocrinology
Advanced skills for paediatric endocrine nurses

• Practical skills
  – Venepuncture / cannulation
    • Dynamic function tests
  – Physical assessment
  – Bone age assessment
• Managing own patient caseload
• Nurse led clinics
Nurse led care

- Outpatients
  - Nurse led clinics
    - Outpatients
    - Telephone
  - Daycare
    - Nurse led investigations
    - GH choice and training
    - Emergency hydrocortisone training

"DO YOU WANT TO SPEAK TO THE MAN IN CHARGE, OR THE NURSE WHO KNOWS WHAT'S GOING ON?"
Benefits of nurse led clinics

- Decreases patients’ waiting times
  - Including the nurse led clinic
  - GH prescribing process
- Increases consultants’ time for more complex patients
- Building stronger relationships with patients and their families
- Enhanced patient satisfaction
Growth hormone and the CNS

Patient choice

Concordance
GH devices
Needle free devices
Knowing our patients

• What is the CNS role in patient choice of growth hormone product?
  – Relationships with families
  – In depth knowledge about the condition
  – In depth knowledge regarding the product
Patient choice – what are the issues?

- Ease of use
- Needle free
- Colour
- Quietness
- Size
- Needle guard
- ‘Feel’
- Automatic needle insertion
- Reduced time holding device against the skin post injection

*Wickramasuriya, 2005*
‘Very useful’ features:
- Pre-programmed dose feature
- Skin sensor
- On screen instructions
- Display of remaining dose
- Confirmation of injected dose
- Automatic needle attachment

*Dahlgren, 2007*
Difference of opinion?

• Various comfort settings
• Dose history
• ‘Teach Me’ menu
• Multi-lingual instructions

• Refrigeration
• Homecare
• Reconstitution
How well do we know our patients?

- Need to understand parental perceptions and beliefs concerning illness and treatment
- Discussions of the patients’ view of the disease and their expectations of the treatment
  - Shown to increase concordance

Spoudeas, 2014; Van Dongen, 2012; Cutfield, 2011; Haverkamp, 2008; Kapoor, 2008
Nurse / Doctor influence?

- Do we always know what is best for our patients?
- Need a thorough, more detailed understanding
- Nurses in the prime position to know the children and their families more closely
  - Families have our contact details
  - Contact us with queries / concerns
  - Main point of liaison for families
But how does this work in practice?

• Children with learning difficulties
  – Septo Optic Dysplasia
    • Need for quick injection → Zomajet
    • Visual problems → Easypod, digital pen devices

• Teenagers
  – Something small, discreet, disposable → Miniquick

• Girls with Turner syndrome
  – Manual dexterity issues → Easypod, Zomajet
  – Larger doses needed → Easypod, Humatropen (20,24mg)

• Travelling families / children with more than one home
  – Think about non-refrigeration → Easypod, Miniquick, Norditropin
But how does this work in practice?

- **SGA**
  - Reduced s/c fat →
    - Want more control over administering the injection
      - No autoinjectors
    - Smallest needle, small vial sizes (4mg, 5mg, 5.3mg)

- **Control taken away** → Easypod

- **Post oncology patients** → Zomajet

- **Fear of needles**
  - Needle free → Zomajet
  - Needle covers / hidden needle → Easypod, Nutropin Aq, Genotropin pen and Miniquick, Nordipenmate, SurePal
How does choice work around the UK?

- Department has limited choice v.
- Free choice of all devices
  - Do we all give patient choice?
    - 89% of 52 centres surveyed do (BSPED audit 2008/2009)
- CNS
  - Chat in clinic
  - Demonstrates all devices
  - Posts out DVDs / patient literature – follow up phone call
  - Clinic appointment

*Informed choice?*
Nurses’ roles – how to increase concordance

- Initial meeting with children and families: Non-judgemental, flexible approach
- Spend time with the child and family:
  - Get to know their concerns and fears
  - Get the concordance agreement right
- Free patient choice of device?
- Enhanced support
- Education for patients
- Nearing adolescence
  - *Opinions on their device may change*..

*Smith, 1992; Haverkamp, 2008; Kapoor, 2008; Cutfield, 2011*
How can we enhance the choice process?

• Involve other patients
  – GH support days
  – Group demonstration sessions
• Courses for children for self-administration
  – Age 10 / 11
• Freedom of choice of all devices
• Explore technology
  – Text messaging
  – Apps

Spoudeas, 2014; Van Dongen 2012; Kirk, 2010
Conclusion

- Paediatric Endocrine Nurse Specialists are in the best position to foster a close relationship with children and their families

- Advanced nursing roles
  - Nurse led clinics
  - Advance patient care with more time
    - Educate the children and families more on their condition, and about GH devices
    - Get to know the families and the implications of their conditions
    - More and more CNSs becoming Independent Prescribers and Advanced Nurse Practitioners

Are we the future...?